

Rhode Island Department of Health

Public Health Briefings

Palliative Care for Cancer Patients: Current Issues

John P. Fulton, PhD

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John P. Fulton, PhD, is Acting Associate Director, Division of Disease Prevention and Control, Rhode Island Department of Health, and Clinical Associate Professor, Brown University School of Medicine.

Objective

In 1996 the Rhode Island Department of Health assembled an Expert Panel on Cancer Treatment to advise the Department on revising the State's current cancer control plan, published in 1989. (1) After a series of discussions, the Panel proposed a number of recommendations for cancer care in the State, including two which address palliative care: Extend and improve patient access to state-of-the-art cancer care, including early diagnosis, prompt multidisciplinary treatment, and support services. Extend and improve application of state-of-the-art cancer care by health professionals, including accurate staging, adequate patient referral for multi-disciplinary treatment, aggressive patient follow-up, and appropriate attention to quality of life and support services. After further reflection, the Chair of the Expert Panel recommended that an Expert Panel on Palliative Care be assembled to address palliative care issues comprehensively. The Department has acted on this recommendation and is in the process of recruiting Panel members. The Panel will be asked to address current issues in palliative care, as identified by the Expert Panel on Cancer Treatment and a recent review of the current literature.

Current Issues in Palliative Care for Cancer Patients

In 1998, 31 years after the founding of the first hospice by Dr. Cicely Saunders in Great Britain, (2) and 24 years after the founding of the first hospice in the U.S. (The Connecticut Hospice), (3) many terminally ill cancer patients (and other terminally ill patients) in this country still do not receive adequate palliative care. As a result, many experience very poor quality of life at the end of life. (2,4) Many live and die in pain. (2,5-7) This failure to meet the needs of the dying has fueled the movement toward physician assisted suicide. (8)

Many reasons have been developed in the literature to explain this complex phenomenon. A few main themes have emerged, and are listed as potential determinants of inadequate palliative care for terminally ill patients:

- Despite increasing recognition of the need to improve the quality of life for terminally ill people, the aggressive pursuit of life-saving measures for terminally ill patients is generally expected and accepted in U.S. society. (4,9,10)
- Despite the desire to maintain a good quality of life and to die with dignity and without pain, many patients and their families have great difficulty accepting an impending death and opting for palliative care in place of more aggressive treatments. (4)
 - Communication among patients, their families, and providers about preferences for care at the end of life is generally inadequate for informed decision making. (4)
- Advance directives may be too vague to guide terminal care. (14)
- Advance directives may go unheeded by providers. (12)
 - Communication among patients, their families, and providers about preferences for care at the end of life is generally inadequate for informed decision making. (4)
- Physicians may have difficulty accepting the impending death of a patient and opting for palliative care in place of more aggressive treatments. (13)

In the main, physicians have inadequate tools for palliative care.

 - Training in palliative medicine is inadequate in most medical schools. (8,4,12,15)
 - Worldwide, there are few centers of excellence for palliative medicine. (16)
 - Palliative care services are not fully integrated into the health care system. (12,17,18)
 - Few oncology centers offer formal training in communication skills. (19)
- Financial incentives and disincentives favor the provision of traditional medical care services over supportive services at the end of life. (20)
- Hospice care, as developed and financed in the U.S., is inaccessible to many terminally ill patients and their families.
 - In the main, physicians are slow in referring patients to hospice care. (12)
 - Physicians may be unaware of hospice benefits. (12)
 - Physicians may not wish to transfer control of patient care to hospice providers. (12)
 - Current hospice benefits mandate that the patient have less than six months to live.
 - It is difficult to establish an accurate prognosis with certain patients. (12,13) As a result, many who would have benefited from services earlier in the course of terminal care are admitted within days of death. (2,21,22)
 - It is difficult for patients and their families to accept an "all or nothing" demarcation between curative care and palliative care. Many cancer patients overestimate their prognoses. (23)

- Few inpatient hospices exist. (8) In many localities, hospice care is only available as home care, requiring round-the-clock care giving by family members in the home. Some terminally ill patients do not have family members available to support them in this way. (12,24-26) Others, with severe physical dysfunction, may not be served best in the home setting, given the resources that are generally available in that setting. (2)
- Hospice care in the U.S. is less accessible in rural and inner-city areas than in other urban and suburban areas. (12)
- Hospices may not employ sufficient numbers of people from ethnic and racial minority groups, creating a barrier to the use of hospice services by members of those groups. (12,25,26)
- Hospice principles of communication may be alien and threatening to people of certain cultures. (12)
- Hospitals and nursing homes, where most terminally ill cancer patients die, may not be prepared to assure effective palliative care for patients in need of it. (2)
- U.S. society as a whole is uncomfortable with the use of opioids for the treatment of pain. (12)
 - Physicians and nurses fear that patients will become addicted to pain medication. (2)
 - Education addressing the control of pain in terminally ill patients is lacking in many medical schools and in many schools of nursing. (2)

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